

# ICARE Epilepsy Research Portfolio Analysis

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## INTRODUCTION

**ICARE**  
Epilepsy research needs reach across the missions of multiple National Institutes of Health (NIH) Institutes and Centers and across many organizations outside the NIH. As the primary NIH Institute for epilepsy research, the National Institute of Neurological Disorders and Stroke (NINDS) leads the Interagency Collaborative to Advance Research in Epilepsy (ICARE) working group. ICARE is a voluntary working group of public and non-profit organizations in the United States that provide sustained funding for epilepsy research and training. Annual meetings provide a forum for sharing information about ongoing and planned epilepsy research activities, highlighting advances and discussing needs and opportunities, and promoting increased collaboration toward common research goals.

**Purpose of analysis**  
As to date no comprehensive analysis of the epilepsy research efforts from all ICARE members had been undertaken, the ICARE group agreed at their meeting on March 24, 2014 to establish a working group tasked with performing a detailed analysis of epilepsy research supported by the member organizations.

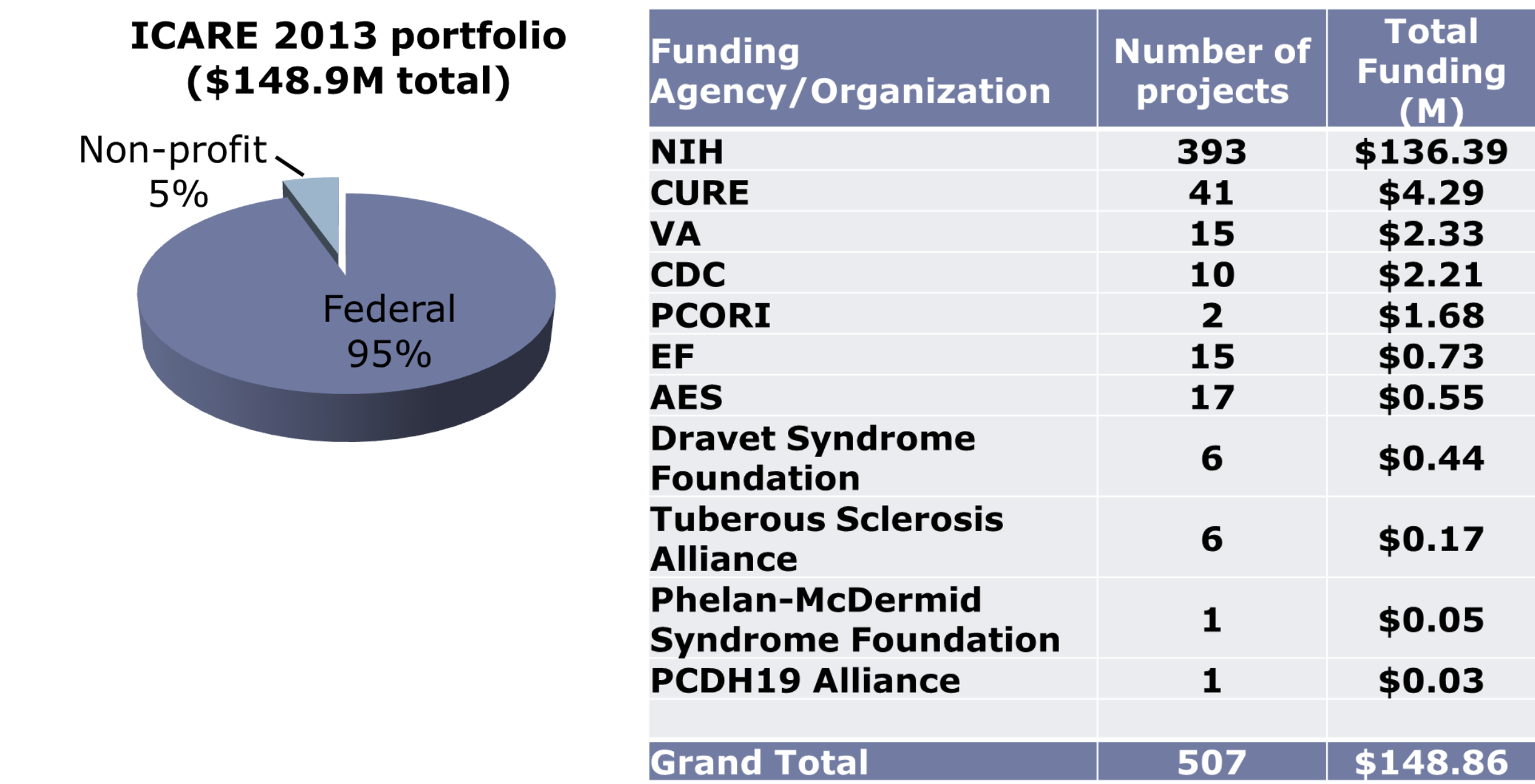
### Goals for a comprehensive analysis

- To better inform the ICARE group and interested public about the funding landscape for epilepsy research.
- To assess progress being made against the epilepsy search priorities as defined by the 2014 NINDS Benchmarks and the recommendations from the 2012 IOM report “Epilepsy Across the Spectrum”.
- To help guide future funding priorities by highlighting current gaps and opportunities in epilepsy research.

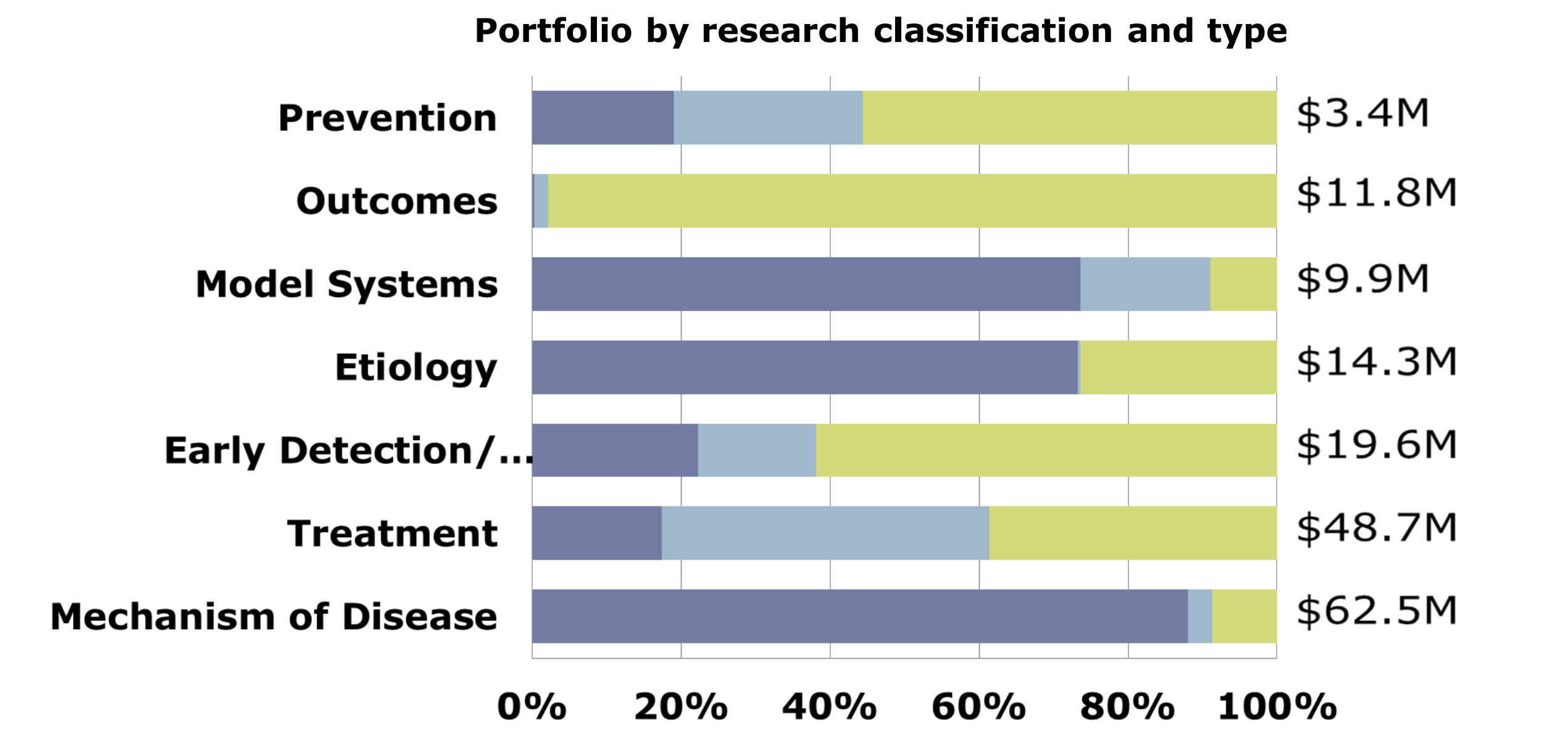
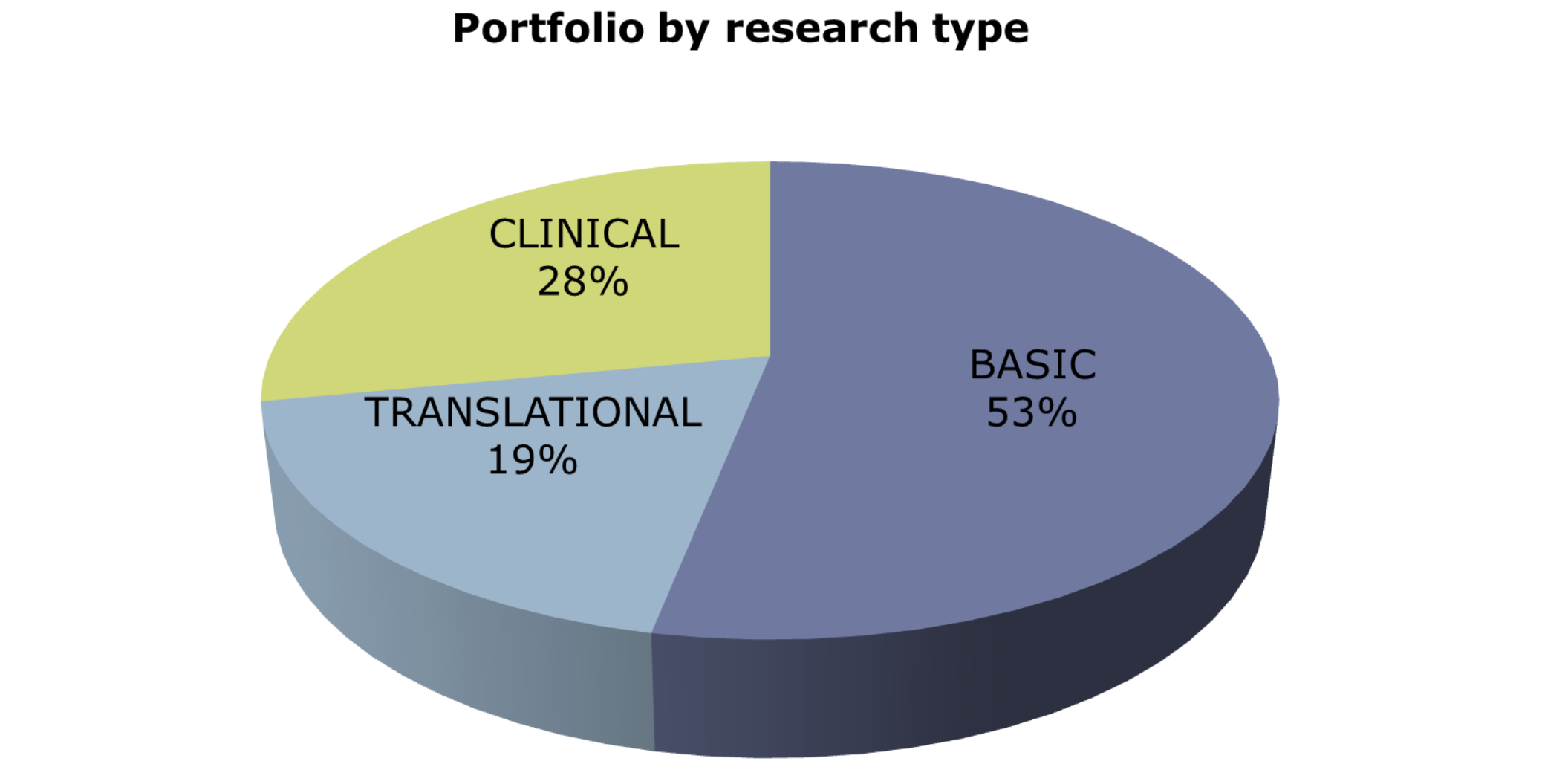
## ANALYSIS DESIGN

- Data was collected in four different areas: 1. Award Information; 2. Award Research Categories; 3. NINDS 2014 Benchmark Areas; 4. IOM 2012 Recommendations.
- The data collection template provided drop-down menu’s for all the categorization fields, with a definition provided for each option of a drop-down menu.
- All ICARE member organizations categorized their 2013 funded epilepsy research projects according to the four areas.

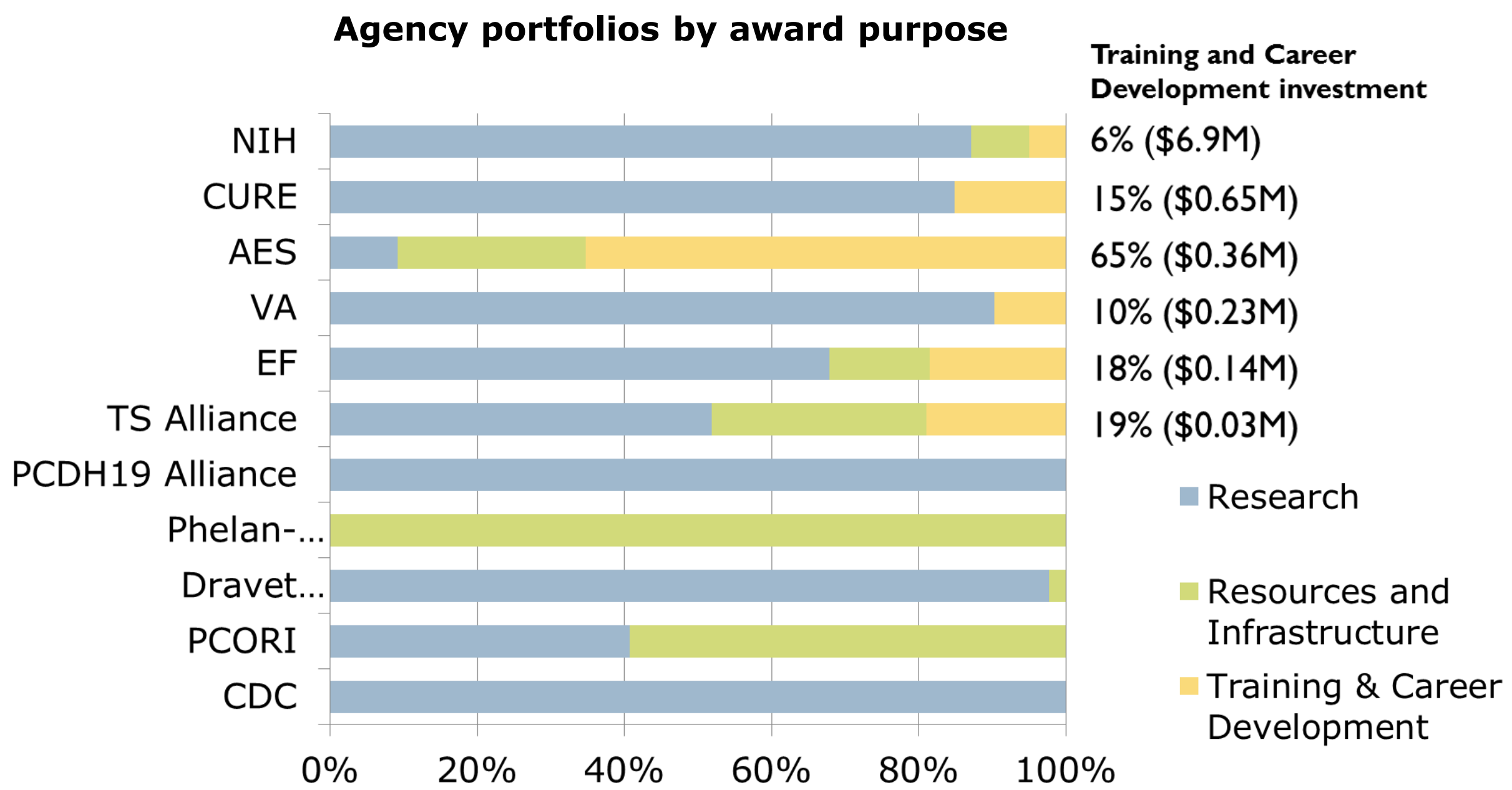
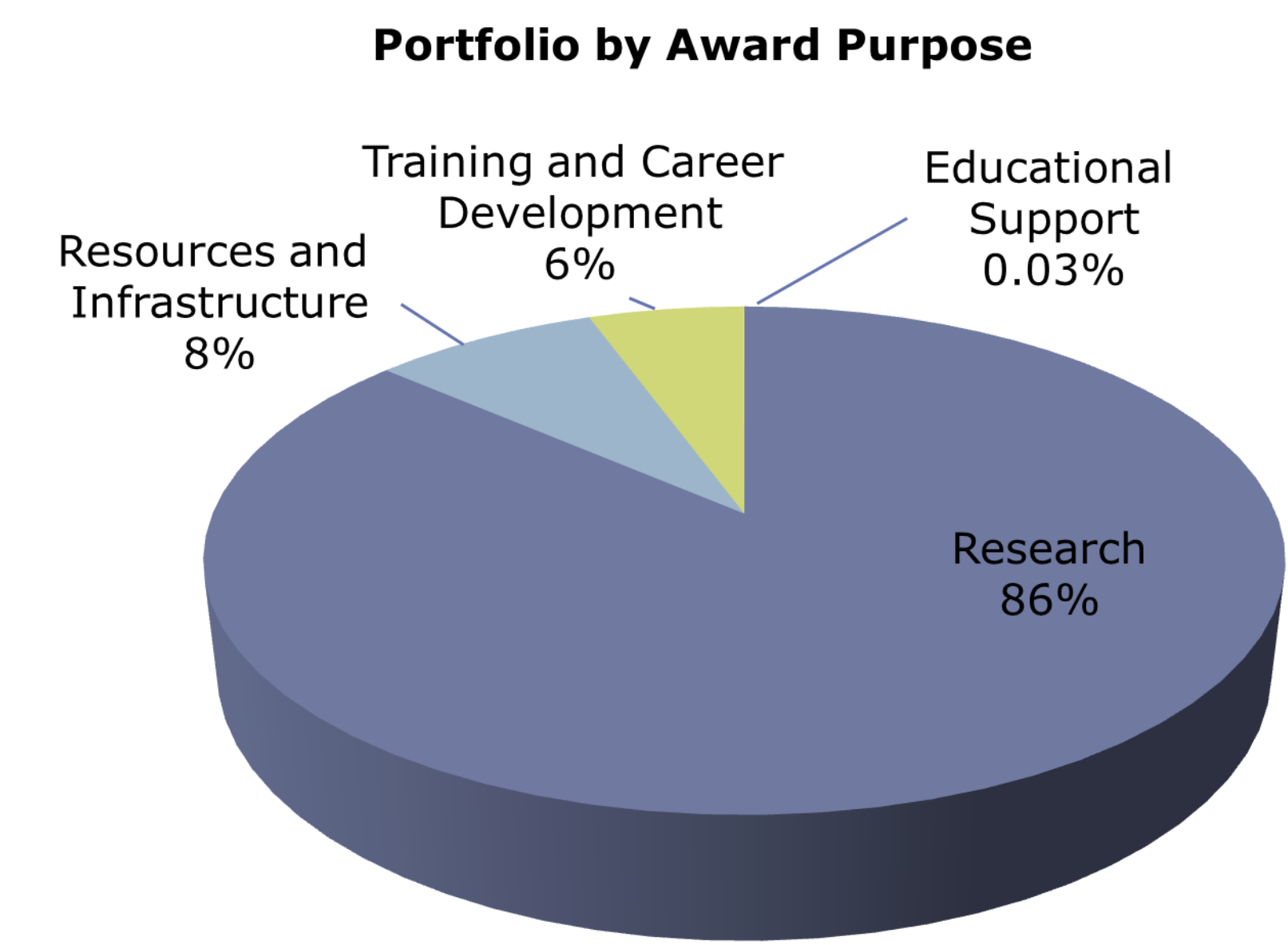
### Federal Funding Dramatically Outpaces Non-profit Funding for Epilepsy Research



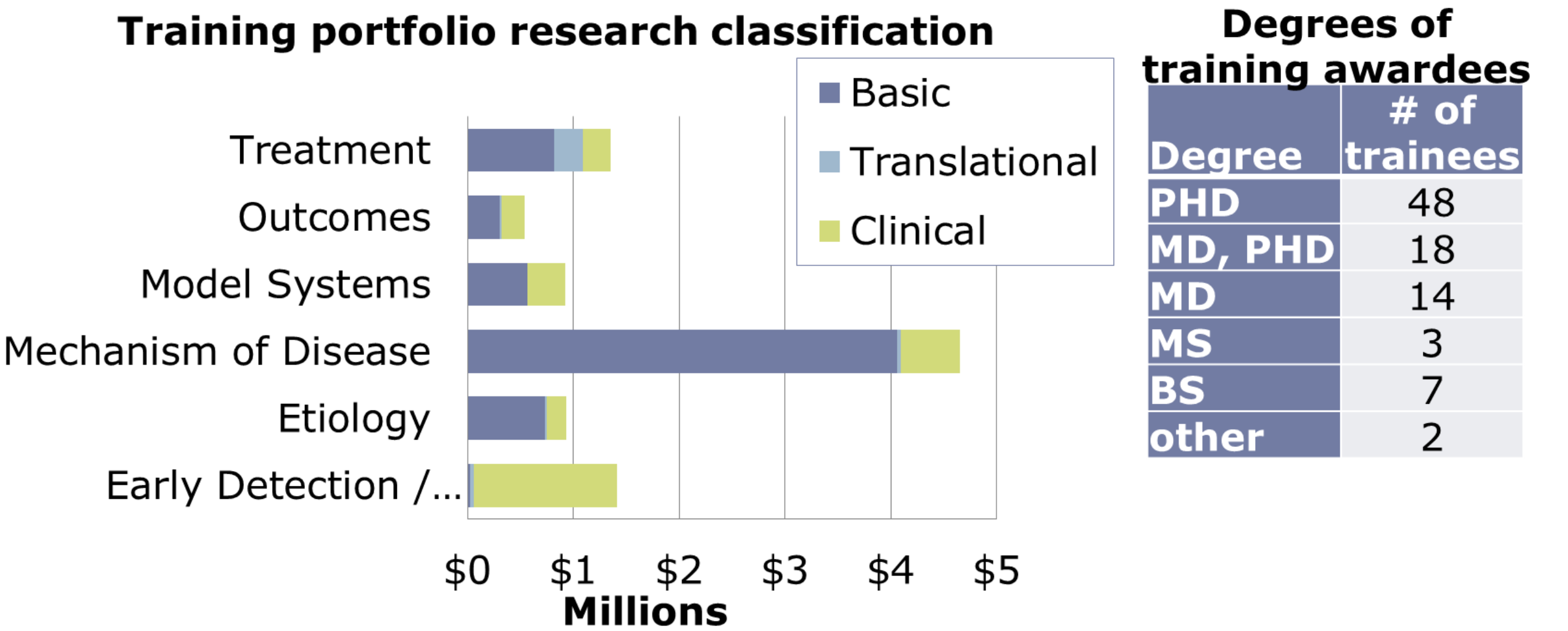
### Most Funded Epilepsy Research is Basic on Mechanism of Disease



### Limited Funding for Structured Training is Provided by a Subset of Organizations

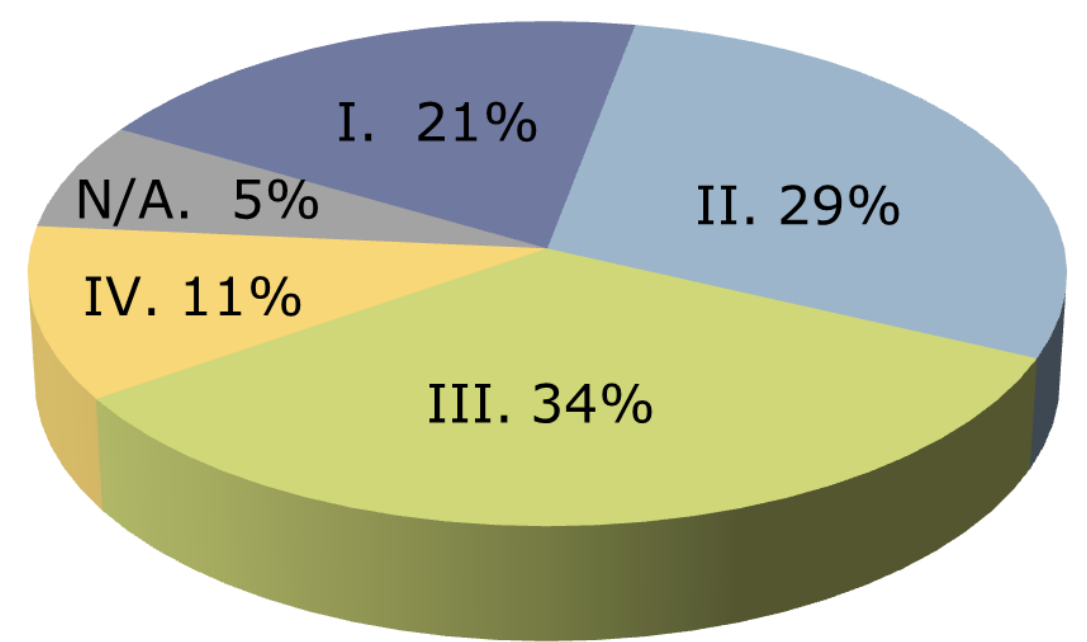


### Majority of Training and Career Development Awards Support Basic Research



### Disparities in Funding Across the 2014 NINDS Benchmark Areas

**Portfolio by 2014 NINDS Benchmark Areas**



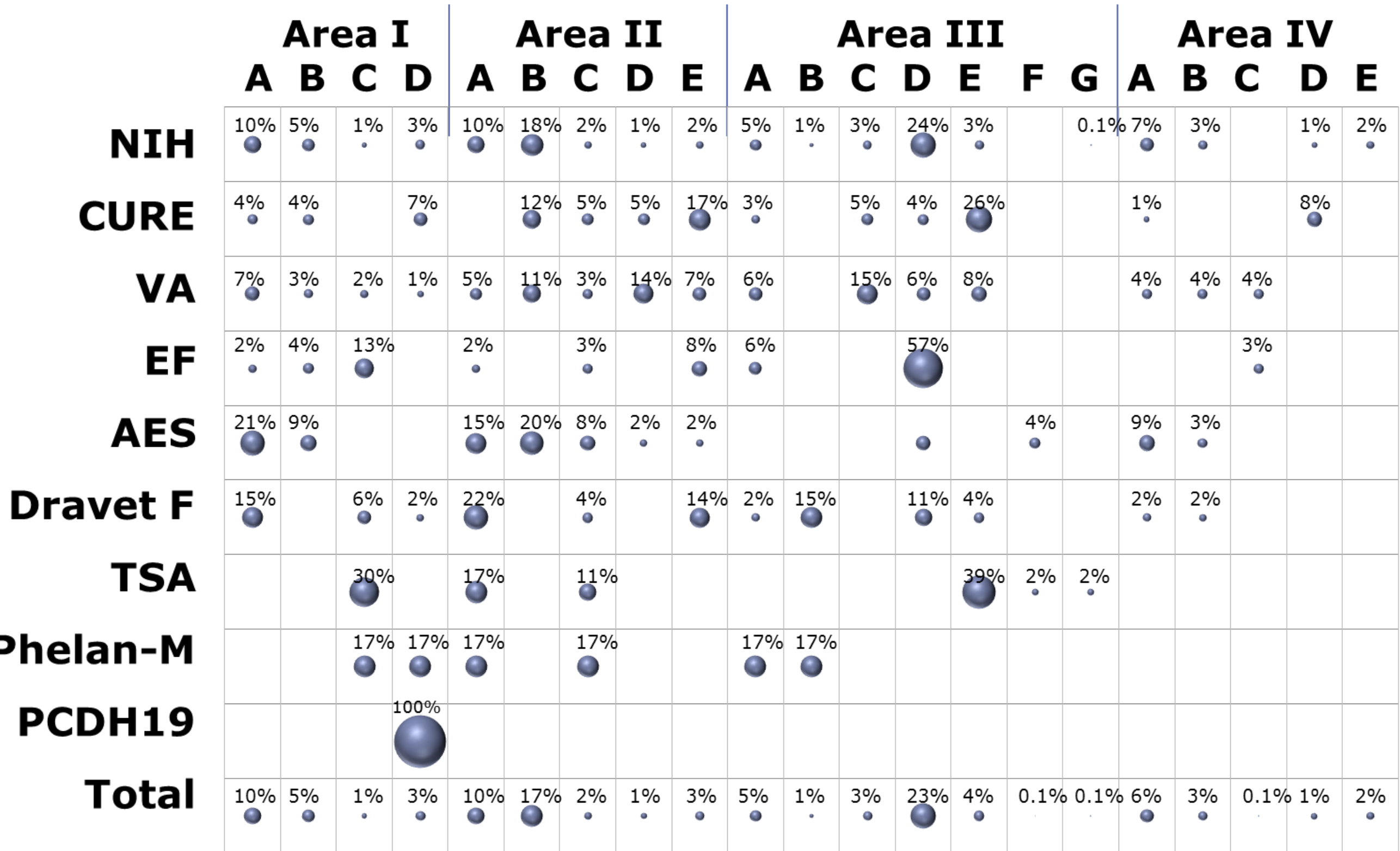
**2014 NINDS Benchmarks for Epilepsy Research**

**AREA I.** Understand the causes of the epilepsies and epilepsy-related neurologic, psychiatric, and somatic conditions.

**AREA II.** Prevent epilepsy and its progression.

**AREA III.** Improve treatment options for controlling seizures and epilepsy-related conditions without side effects.

**AREA IV.** Limit or prevent adverse consequences of seizures and their treatment across the lifespan.



## CONCLUSIONS

Results from the first comprehensive landscape analysis provide valuable insights into the current epilepsy funding landscape.

- 1) Epilepsy research funding spans a range of organizations with different missions and funding capacity.
- 2) Federal funding, highly concentrated at NIH, significantly outpaces nonprofit research funding.
- 3) Majority of funding supports Basic research on mechanism of disease.
- 4) Limited support for structured training in epilepsy research.
- 5) Epilepsy research funding is unevenly distributed among the Epilepsy Benchmark priorities.

The results form a basis for future trends in epilepsy research, which will be monitored on a yearly basis by the ICARE group.